Hope After Failure: Heart Failure Patient Education

An Honors Thesis (HONR 499)

By

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Abstract

This study aims to investigate the effectiveness of heart failure patient education at IU Health Ball Memorial's Heart and Lung Center. Heart failure falls under the category of cardiovascular disease, which is the number one cause of death for both men and women in the United States. Patients experiencing heart failure are likely to readmit to hospitals, causing the implementation of the Hospital Readmissions Reduction Program (HRRP) by the Affordable Care Act, which penalizes hospitals for having high numbers of 30-day readmissions. Hospitals across the country are working to prevent heart failure patient hospital readmissions by improving their patient education; however, one best method has not been found. The main purpose of this study is to identify the information patients are and are not retaining, when they prefer to hear information about their diagnosis, and their likelihood of attending the Heart Failure College program at the hospital. In this study, 26 patients seen in the Heart Lung Center completed an in-patient survey, and seven patients seen at home by the community paramedic completed an out-patient survey. Results suggest that patients are familiar with most topics linked to their heart failure diagnosis with the exceptions of heart failure zones of care, mood changes, and palliative care. Most patients preferred learning about disease management on the day of their diagnosis as opposed to after the first appointment post-discharge. In addition, many patients stated they would not attend Heart Failure College due to the time commitment; however, they would prefer to receive the same information via paper reading materials or discussions with Heart Failure College educators by phone.

Acknowledgments

I would like to thank Dr. Melinda Messineo for not only advising this project, but also for introducing me to the Heart and Lung Center and being my personal cheerleader throughout this year. I am extremely thankful for the guidance and support she provided.

I would also like to thank Kari, Leroy, and Katrina for allowing me to perform my study at the Heart and Lung Center and invade their space for a month.

Table of Contents

Process Analysis Statement

Through my years as a pre-medical preparation undergraduate student at Ball State University, I have been exposed to the healthcare field in various facets, and when the opportunity arose to continue to delve deeper into a single specialty, I jumped at the chance. Prior to this experience, I had explored a variety of physician specialties; however, I had not explored cardiology. Although research in the lab context often makes pre-medicine students competitive for medical school, it did not particularly interest me. I felt as though if I could not passionately discuss the work I had spent long periods of time on, it would not provide me an advantage in my interviews. I believed the biggest impact I could make involved working with individuals firsthand, which directly aligns with my career goal. Due to this, I was intrigued when Dr. Messineo introduced the needs of IU Health Ball Memorial's Heart and Lung Center to me.

IU Health Ball Memorial Heart and Lung Center continues to try to improve the lives of their patients, and one of the ways they do this is through their Heart Failure College. Heart Failure College is a program that is free to patients and caregivers of patients who have been diagnosed with heart failure. Patients are educated on their diagnosis and how to manage it by many healthcare professionals such as nurses, nutritionists, and pharmacists. Some of Dr. Messineo's previous students collaborated with the Heart and Lung Center to gauge the effectiveness of the program and how receptive heart failure patients were to this method of education on their diagnosis via patient surveys. Although Dr. Messineo's previous students compiled the data and presented it the Heart and Lung Center healthcare professionals, the goal of overall improvement did not end there: The Heart and Lung Center was still looking for more ways to improve their patient education outside of Heart Failure College.

The process began by collaborating with Katrina Riggin, the manager of Cardiac Ancillary Services at IU Health Ball Memorial, to discuss the needs of the Heart and Lung Center. Two surveys were created and approved by the Heart and Lung Center, but the program evaluation did not begin directly after this.

After working through all of the logistics and planning that this project involved, an Institutional Review Board (IRB) Human Subjects Research Protocol was submitted, as human subjects would be answering the surveys. After the initial submission, it was requested that revisions were made to clarify the parameters of the study. Revisions were submitted and a decision was made that this project did not fall under the umbrella of Human Subjects Research; therefore, it could proceed without further engagement with the IRB. This project was not considered Human Subjects Research because it was a program evaluation where IU Health Ball Memorial would be presented the information in aggregate form and only use it internally to improve their heart failure education. The back and forth between the IRB pushed the timeline back; however, it was necessary to err on the side of caution before starting the study in order to protect the patients involved.

When it came time to start administering the survey, I was able to sit in at the Heart and Lung Center all day at the beginning of the data collection period, as it was spring break; however, once school started back up, I was only able to visit the center twice a week in the afternoons for a total of five or six hours each week due to my schedule. This hindered my ability to efficiently collect surveys, as many of the patients during the afternoon slots cancelled or no-showed their appointments. My limited availability also made it difficult to visit patients' homes with the community paramedic to administer the out-patient survey, as it did not usually correlate with the times he was leaving the center. It was already anticipated that this would be

an issue prior to data collection, and was discussed with Katrina. The solution was to have the Ball State University exercise science interns who were in the Heart and Lung Center rotation to administer in-patient and out-patient surveys during the week when I was unable to be there. Unfortunately, as the interns rotated in and out of the center or were busy working with the patients, they were unable to administer surveys.

As this research was performed in the field, as opposed to in a controlled laboratory scenario, it was not unusual that this is the way the project progressed. Whether or not the patient agreed to participate in the survey or whether or not the parties involved were focused on administering the survey was not under the researcher's control. In-field studies can be messy and unpredictable, which can alter the timeline and details for the researcher and forces them to be flexible with these changes, and that is exactly how this study progressed. Working with multiple groups of people at different times of the project takes the control out of the researcher's hands and slows down the process a bit due to those being involved understandably having priorities that come before this project. Therefore, although there were kinks to work out throughout the process of this project, they were normal gauges of how in-field research works and did not lead to an unsuccessful study. A lower number of surveys than projected were able to be collected before the hard deadline; however, the quality of the surveys and the results gained from them were not lacking.

Through the data collection process, I learned how even precisely planned events may not have progressed the exact way I wanted them to, but it was important to not let the unforeseen problems ruin my outlook on the research I was doing. In the end, I was still able to collect a fair number of in-patient surveys that provided a rather common perception of the Heart and Lung Center's effectiveness of educating their patients.

Overall, this has been a fulfilling experience for me. This program did give me insight on how much patience is required to be involved in collaborative research because waiting for confirmation and approval from all parties involved at different points can be difficult to achieve in the desired time frame. However, I thoroughly enjoyed research in the clinical setting, as I thought I would, due to the amount of patient interface I was exposed to. Having the ability to interact with individuals while performing helpful research was fulfilling because it remained yet another affirmation that I want to work in medicine to improve the lives of patients.

Introduction

THE HEART

The heart is a vital organ, and without some form of it, life for humans cannot occur. It functions as a pump that provides all necessary locations of the body with fresh oxygenated blood. The heart functions with the lungs, arteries, and veins to ensure this process is completed correctly. Within each heartbeat, a number of events occur. Blood flows through the atrium and ventricles of the heart with precise maneuvers, but the movement is only in a single direction that is directed via the cusps of the heart valves (“How the Heart Works,” 2017). The superior and inferior vena cava, veins that lead to the heart from the upper and lower regions of the body respectively, fill the right atrium of the heart with oxygen-poor blood. Blood from the right atrium passes through the tricuspid valve and is forced into the right ventricle of the heart when the atrium contracts. The right ventricle then contracts, causing the blood to flow into the pulmonary arteries after passing through the pulmonary valve, which makes the “dub” sound of the heartbeat. The contraction of the right atrium then follows.

Once the blood reaches the pulmonary arteries, it travels to the lungs where oxygen that has been obtained through breathing is complexed into the red blood cells within the blood. The blood is now oxygen-rich and can travel back to the heart, filling the left atrium via the pulmonary veins. Contraction of the left atrium when it is full pushes blood into the left ventricle through the bicuspid valve, creating the “lub” sound of the heartbeat. Finally, the left ventricle contracts and pushes the blood out of the heart and into the aorta where oxygen can be carried to organs around the body via the arteries. Cells that make up the various organs of the body will receive oxygen-rich blood, obtain the oxygen, and send the deoxygenated blood back to the vena cava and heart from the veins. This cyclic process is repeated over and over again as each

heartbeat occurs because cells are constantly in need of oxygen to complete their functions ("How the Heart Works," 2017). The knowledge of the complexity of the heart and its careful orchestration leads to the question: What can occur when the heart loses some of its ability to function properly?

Cardiovascular disease, which is also known as heart disease, is the leading factor of death in both men and women in the United States, and characterizes a number of diseases that fall under the umbrella of heart and blood vessel diseases ("Heart Disease Facts & Statistics," 2017). Under this broad category, heart failure is present. Heart failure is defined as the heart muscles' inability to pump blood effectively. The heart does not function as it should with the workload it is given, and therefore, the body may not be able to receive adequate amounts of oxygen ("Heart Failure," 2017). Contrary to what some believe (or the name implies), heart failure is not when the heart completely fails or stops. Key signs and symptoms of heart failure include shortness of breath while exercising or laying down, lower extremity swelling from fluid retention, continuous coughing with white or pink mucus, fatigue, confusion and decreased alertness, depression, chest pain, and increased heart rate ("Heart Failure", 2019).

Although some victims of heart failure may be unaware of how it happened, there are underlying causes that contribute to heart failure. Other heart conditions, especially coronary artery disease, heart attacks, and high blood pressure can drive the onset of heart failure ("Causes and Risks for Heart Failure," 2019). Increased age also increases the likelihood of being affected, and men are more frequently affected than women (Bui, Horwich, & Fonarow, 2011).

The damage done to the heart that causes heart failure unfortunately cannot be cured, only managed; therefore, when a patient is diagnosed with heart failure, they will be living the rest of their life with the disease and its side effects.

Heart failure is a serious disease, affecting one in five adults over the age of 40 and with over 550,000 people being diagnosed each year in the United States (Bui, Horwich, & Fonarow, 2011). Nationally, over six million people in the United States are living with heart failure, and it is expected to increase to eight million by 2030 ("Understand Your Risk for Heart Failure," 2019). Collectively, over 23 million people are living with heart failure worldwide (Bui, Horwich, & Fonarow, 2011).

These dramatic statistics display how widespread of an issue heart failure is, but what are some of the implications of heart failure? At an individual level, the risks associated with heart failure are decreased quality of life, as well as decreased life expectancy. Another issue that stems from heart failure, but on a more societal level, is that of hospital re-admittance and its cost.

HEART FAILURE AND QUALITY OF LIFE

Treatment of heart failure aims to alleviate symptoms and improve the patients' quality of life by maximizing their daily function. Quality of life does not have a universal definition that is used by all healthcare providers; however, a common definition of health related quality of life (HRQL) is the patient's perspective of their life experience with illness (Coelho, Prata, Bettencourt, Ferreira, & Cerqueira-Gomes, 2005). HRQL does not simply include a patient's physical function, but also their occupational function, symptoms of discomfort, perception about their health, psychological function, social function, and vitality (Coelho, Prata, Bettencourt, Ferreira, & Cerqueira-Gomes, 2005). When patients are asked to define what quality of life looks like to them, they often prioritize retaining their ability to engage in regular physical and social activities, maintain happiness, and participate in rewarding relationships with

others (Heo, Lennie, Okoli, & Moser, 2009). For example, most individuals want to be able to leave the house to go shopping with their friends or be able to provide themselves with basic care, such as bathing or cleaning, with all or at least some independence; however, with heart failure, doing some of this will not always be possible. Heart failure is one of the leading chronic diseases that affects HRQL; moreover, not only does quality of life decrease when an individual is not able to perform all of the activities they previously could without difficulty, but also when hospital readmissions are factored in (Rodríguez-Artalejo, Guallar-Castillón, & Pascual, 2005).

When individuals are hospitalized due to heart failure, their life expectancy is estimated to likely be only five years Bui, Horwich, & Fonarow, 2011). Individuals diagnosed with cancer also have this estimated life expectancy, but the attitudes toward heart failure versus cancer outlooks differ ("Life Expectancy," 2015). This may be due to the differences in course of treatment between the two. Cancer patients' treatments are often out of their direct control, and they have to turn to surgery, chemotherapy, and radiation; however, heart failure patients' treatment is linked more closely to their own actions. Management of heart failure symptoms include lifestyle changes including quitting smoking, tracking fluid intake, eating a diet compliant with the heart's needs, limiting caffeine and salt, monitoring blood pressure, and being physically active ("Lifestyle Changes for Heart Failure," 2017). In a study performed comparing heart failure and cancer-related survival, in comparison with most common types of cancer, excluding lung cancer, a first admission for heart failure is associated with a worse survival rate; however, these results do not seem intuitive because heart failure patients should technically have more control over their prognosis (Stewart, MacIntyre, Hole, Capewell, & McMurray, 2001).

While personal responsibility of creating a healthier everyday routine may objectively seem less daunting and more dependable than cancer treatment, it may not feel that way to the heart failure patient. Although each change may seem minor compared to saving one's life, altering someone's daily practices can be overwhelming and intimidating. The above changes can possibly extend the five-year life expectancy and decrease the chances of heart failure reoccurrence; however, patients often fail to see the seriousness of their condition. This could be attributed to lack of understanding their diagnosis, even with detailed consultations by healthcare professionals.

HEART FAILURE READMISSIONS

In order to assist heart failure patients in learning how to live with their diagnosis, palliative care is often a choice. As defined by the World Health Organization, palliative care works to prevent and relieve painful symptoms of patients with a chronic illness through a variety of means to increase both the patient's and their family member's quality of life ("WHO Definition of Palliative Care," 2019). Most people who have heard of palliative care only associate it with its goal to decrease physical symptoms, but do not think of the other components. Palliative care teams provide emotional and spiritual support to the patient and their family, as well as help the patient understand their options for treatment. As palliative care's goal is to improve quality of life, they help the patient make decisions that correlate with their wishes for the rest of their life.

Often times, palliative care is associated with hospice, and while they both have similar goals, they are different. Hospice is characterized as end-of-life care, and making sure the patient is as comfortable as possible when it comes time for death when additional treatment is no longer

an option. Palliative care can begin right after a serious medical diagnosis is made, and can continue while a patient is receiving treatment. In addition, because many patients group palliative care and hospice together as end-of-life care, there is a negative stigma towards palliative care. Patients are reluctant to receive this form of care because they think it means they are dying soon, even though this is not usually the case (Lane, Ramadurai, & Simonetti, 2019). The lack of awareness and understanding of palliative care could also prevent patients from knowing it is an option to pursue. For patients with heart failure, a serious illness, palliative care is a great opportunity to help maximize functioning and learn how to live day to day with their new diagnosis.

When looking at the societal level of how heart failure affects more than just the individual, its result on the healthcare system is more than likely the first to come to mind. Patients who have heart failure are likely to be readmitted to hospitals within 30-days for many reasons; consequently, causing the overall readmission rates of the hospital to increase. This in itself becomes an issue for two main reasons. Readmission is associated with lower quality of care because if a patient was diagnosed and treated properly, they should not be returning to the hospital within a short time frame after being discharged. The other issue is how much it costs to continually treat readmitted patients. In order to address these issues, insurance companies have created policies where they will pay-in less to the hospital for a patient's course of treatment if they have been readmitted within the 30-day window to create more quality care and reduce preventable expenditures (McIlvennan, Eapen, & Allen, 2015).

The Affordable Care Act introduced the Hospital Readmissions Reduction Program (HRRP) in 2012, which financially penalized hospitals if patients with acute myocardial infarction, heart failure and pneumonia were readmitting within 30-days at a higher than

expected level. The HRRP also established that Centers for Medicare and Medicaid Services (CMS) were required to reduce their payments to hospitals who had excess readmissions and were also IPPS-participating hospitals (McIlvennan, Eapen, & Allen, 2015). Inpatient-prospective payment system (IPPS) is a system that pays for inpatient stays and outpatient services related to their diagnosis or admission and is paid to the hospital on the date of the patient's admission or within three days immediately preceding the date of admission (McIlvennan, Eapen, & Allen, 2015). As readmissions due to heart failure remain high for almost all healthcare systems, these penalties place stress on the hospitals to find ways to limit readmissions of their patients.

Many of the readmissions for heart failure are preventable and can often be linked to failure of medical professionals to provide adequate education or target high-risk patients, or it can be due to the patient not following the course of treatment and diet for a number of reasons; therefore, it may be suggested that there is a disconnect between medical professionals and their heart failure patients (Strömberg, 2005). The traditional model of educating patients follows the idea that teaching patients increases their knowledge, and this knowledge leads to better self-care behaviors, which will then lead to decreased mortality rates over time. This traditional method, however, neglects the fact that more than knowledge is needed to manage heart failure. Patients need to understand, reflect, and feel autonomous in the learning process (Strömberg, 2005). Barriers to learning may include functional or cognitive limitations, misconceptions and lack of basic knowledge about heart failure, low motivation, and low-self esteem (Strömberg, 2005). To overcome these barriers, medical professionals need to implement strategies tailored to each individual's needs in order to effectively educate them and help them meet their health goals.

READMISSION REDUCTION PROGRAMS

The task of finding methods to prevent 30-day readmissions is a large one that many healthcare systems have been experimenting with, and no one best method has been adopted by all hospitals across the board. Project RED (Re-Engineered Discharge) is a group located at Boston University's Medical Center that is working to develop ways to reduce readmission rates ("Project RED (Re-Engineered Discharge)," 2014). Similar to many other hospitals across the country, they are trying to achieve this by improving the hospital discharge process. Their program includes 12 step-wise components: (1) establish if there is a need for and acquire language assistance, (2) make follow-up appointments and tests for the patient, (3) plan for follow-up with the patient on lab tests that have not come back when they are ready to discharge, (4) arrange outpatients services and equipment the patient will need post-discharge, (5) identify the proper medications the patients will need and plan for the patient to receive and take them, (6) resolve the discharge plan with national guidelines, (7) teach the discharge plan to the patient in a manner they can understand, (8) educate the patient on their diagnosis, (9) assess how well the patient understands the plan, (10) review how a patient should handle a problem if it arises, (11) quickly transmit the discharge summary to the healthcare providers the patient will be following up with, and (12) provide phone reinforcement of the discharge plan ("Project RED (Re-Engineered Discharge)," 2014). The RED program also includes a virtual patient advocate named "Louise", who educates patients in a style similar to nurses about components of their care, such as their prescribed medications, follow-up appointments and diagnoses. There is a RED Toolkit that provides informational videos regarding topics such as what the RED Toolkit is and how hospitals can implement their program into their facility.

The Cardiovascular Prevention and Rehabilitation Program at Toronto Rehab has a program called Cardiac College that provides patients with extensive knowledge of all aspects related to heart disease. Patients can access two on-site rehabilitation centers or online videos and resource guides to explain information they may have previously not understood ("Welcome to Cardiac College", 2019). The benefit to this program is that patients can pick which method of heart failure education they prefer or learn best with, and can pursue that option. For example, if a patient does not have time to go to the Rehab Center for classes, they can learn about heart failure through watching the online videos. Conversely, if the patient learns best by talking in person to a medical professional, they also have the opportunity to do so.

One study performed in various in-patient settings around the world, including the United States, performed trials on which type of transitional clinical care interventions for adults with heart failure was most effective at preventing readmissions at 30-days and between three to six months. They included home-visiting programs, simple telephone technology to monitor or educate the patient, out-patient based clinics, primarily educational, and telemonitoring, which is monitoring physiologic information such as blood pressure or pulse oximetry remotely (Feltner et al., 2014). These methods of interventions were compared to usual care. Overall it was found that home-visiting programs and out-patient clinics that were multi-disciplinary or specific to heart failure (MDS-HF) reduced the all-cause readmissions from three to six months. The others were not effective in this area. For heart failure specific readmissions, both home-visiting programs and telephone technology reduced the risk. Telemonitoring did not reduce this risk, and all other interventions had insufficient evidence. Overall in this study, home-visiting programs and MDS-HF clinic interventions provide the best evidence of reducing readmissions

and mortality up to six months after a hospitalization, but this evidence was lacking when looking at reducing 30-day readmissions (Feltner et al., 2014).

THE HEART AND LUNG CENTER

IU Health Ball Memorial Heart and Lung Center is actively working to keep their patients informed on their diagnosis in a manner where the patients are able to effectively self-manage their condition in order to reduce the number of patients with heart failure diagnoses readmissions to the hospital within 30-days. They have implemented a system that works intricately with their patients. The focus is not solely on the discharge process, but stresses the importance of post-discharge continuation of care, and uses methods similar to the home-visiting program and MDS-HF clinic interventions previously discussed. A nurse practitioner regularly sees patients post-discharge during normal nine to five clinic hours on-site at the Heart and Lung Center. She also rounds to see patients who have just been admitted to the hospital for heart failure. A community paramedic is also part of the team and goes out to patients' homes to assist them with their needs and monitor them. Patients who are a part of this program and who are concerned about their health for any reason on a given day have the ability to get an appointment with the nurse practitioner usually within a day or with the community paramedic usually on the same day. They believe that keeping close contact with the patients ensures all of their heart health needs are addressed and met within a timely manner, and that this factor is imperative to preventing hospital readmissions.

The Heart and Lung Center also provides a program called Heart Failure College. It is a free and voluntary program with the goal of educating patients with heart failure, as well as their caregivers, in order to improve the quality of care that the hospital provides, the quality of life

and the life expectancy of the patients, and reduce hospital admissions in heart failure. Sessions are led by nurses, nutritionists, and pharmacists to provide disease management skills.

Overall the purpose of this research is to perform a program evaluation of the effectiveness of the center's educational materials, specifically for heart failure patients. This program evaluation determines which methods of education about heart failure are best understood by patients at IU Health Ball Memorial. The information gathered from the surveys are used to determine this and presented to Ball Memorial Heart and Lung Center staff, so they can understand what mode of education is most effective for their patients, and can consequently make changes to their internal education of heart failure. As the patients were screened post-discharge, a measurement could be made on how effective the hospital was at conveying important information to the patient in a manner where the information was understood and remembered by the patient. The research question is: Which materials and delivery methods are considered most accessible to and are most retained by heart failure patients? Based on previous research findings, I hypothesize that the information told by the paramedic or practitioner after the event will be better understood and retained compared to the information received immediately at the time of the incident.

Materials and Methods

A collaborative relationship was established with IU Health Ball Memorial Heart and Lung Center. Prior to beginning the study, all materials were submitted and exempt by the Institutional Review Board (IRB). Two surveys, an in-patient survey and an out-patient survey, were created to fit the needs of the Heart and Lung Center in order to reach all of the patients

they see. The surveys were anonymous, so no identifying information was collected. All patients who were surveyed had to fit the criteria of having being previously diagnosed with heart failure.

Patients seen on-site at the Heart and Lung Center were given the in-patient survey. For the in-patient survey, after the patients finished their appointment with the nurse practitioner at the Heart and Lung Center, the principal investigator or IU Health Ball Memorial interns went into the patient rooms to explain the purpose of the survey. It focused on the patient's lifestyle perception, how prepared the patient felt to manage their disease, their familiarity with Heart Failure College, and whether or not they could recall previously hearing certain information from medical professionals about their diagnosis. The survey was administered to the patient verbally. 26 in-patient surveys were collected.

Patients who were visited at their homes by the community paramedic from the Heart and Lung Center were given the out-patient survey. For the out-patient survey, during the patients' visits from the community paramedic in their homes, the principal investigator, IU Health Ball Memorial interns, or the community paramedic administered the surveys verbally. It focused on the patient's familiarity with Heart Failure College, when and how they would prefer to be educated about their diagnosis, and whether or not they could recall previously hearing certain information from medical professionals about their diagnosis. Seven community paramedic surveys were collected. After the data was collected, it was compiled into an aggregate form and used to present to healthcare professionals in IU Health Ball Memorial's Heart and Lung Center.

Results

For the in-patient survey a total of 26 patients were surveyed. The average age of the patients was 65.2 years old. Male patients made up 61.5% of patients surveyed and females made

up 38.5%. A little over half of the patients were married, with the remaining half evenly split between either being single, a widow or widower or being separated or divorced. Most patients had a family doctor at 92.3%. The employment status of 69.2% of patients was retired, disabled, or another type of unemployment, while 23.1% of patients worked full time and 7.7% worked part time. The majority of patients did not receive higher education, with 23.1% with less than a high school diploma, 26.9% with a high school diploma, and 30.8% with some college. Of those remaining, 7.7% went to technical school, 7.7% received a bachelor's degree, and 3.8% received a master's degree. No patients had received a PhD, MD, or JD.

When asked what medical issue brought them to the center that day, 19 individuals recognized they were at the Heart and Lung Center for heart failure, six for heart attacks, three for lung issues, and one was unsure of exactly why they were there. The average amount of times the patients had been treated in the hospital or emergency room for their condition was 7.6 with the low being zero and the high being over 70 times. When asked how active they would say they are on a scale of one to ten, the average was 4.6. When asked how nutritious their diet was, the cohort's average was 7.4. Information patients could recall receiving from medical professionals, with the ability to choose all that applied, were as follows: 96.2% recalled nutrition, 100% recalled medication, 96.2% recalled daily weight, 92.3% recalled exercise, 73.1% recalled heart failure zones of care, and 57.7% recalled mood changes. On a scale from one to ten, the average score of how prepared patients felt to manage their heart health was 7.8. Fifty percent of patients had a caregiver, most of which being a family member. The percentage of patients who had heard of Heart Failure College was 53.9%, with 34.6% stating they had not heard of it and 11.5% stating they were not sure if they had heard of it before. When asked what the name of the program, Heart Failure College, made them instinctively think of, most

associated it with a way to learn more about heart failure at 65.4%, while others associated it with fatality, heart attacks, or as unappealing. After hearing an explanation of Heart Failure College, 23.1% said they planned on attending, while 76.9% did not or were unsure. The main reasons for not planning on attending Heart Failure College included not having enough time, not being able to leave work, not having interest in attending, being able to receive the same information elsewhere, and already attending the cardiac rehab program at the hospital. Of the six who stated they were interested in attending, three said they would have a caregiver or loved one attend the program with them. When asked whether they had heard of palliative care before, 76.9% patients said no or not sure and 23.1% said yes. Some of the patients who had heard of palliative care could not come up with a definition, while others defined it as comfort care, care one receives after surgery or recovery, hospice, or care one receives at the end of their life when no cure is available. Only 7.7% of patients recalled being approached about receiving palliative care. When asked if they had enough resources to self-manage their health, 88.5% answered yes and 11.5% answered no. All patients were then asked the question “what do you need?”. Those who did respond had similar answers: financial assistance, a caregiver, and insurance help. Others needed more clarifications about their diet, or simply wanted to feel better.

Table 1. Demographic information for patients who completed the in-patient survey.

Average Age	65.2 years old
Sex	
Male	61.5% (n=16)
Female	38.5% (n=10)
Marital Status	
Married	53.8%
Single/Widowed/Widower	23.1%
Separated or Divorced	23.1%
Family Doctor	
Yes	92.3%

No	7.7%
Employment Status	
Employed Full Time	23.1%
Employed Part Time	7.7%
Retired, disabled, or another unemployment	69.2%
Unemployed, but looking for a job	0.0%
Highest Education Level Completed	
Less than high school diploma	23.1%
High school diploma	26.9%
Some college	30.8%
Technical school	7.7%
Bachelor's degree	7.7%
Master's degree	3.8%
PhD or MD or JD	0.0%

For the out-patient survey, seven surveys were given. The average age of the patients was 68.7 years old. Male patients made up 85.7% of patients surveyed and females made up 14.3%. Over 70% of the patients were married, with the remaining being single, a widow or widower. There was a relatively even split between those who did and did not have a family doctor at 57.1% and 42.9% respectively. The employment status of 85.7% of patients was retired, disabled, or another type of unemployment, while 14.3% of patients worked full time. Most patients did not receive higher education, with 28.6% with less than a high school diploma, 42.9% with a high school diploma, 14.3% with some college, and 14.3% with technical school.

All patients surveyed were receiving care for heart failure via the community paramedic. Of the seven surveys that were administered, 71.4% of the patients answered the survey on behalf of themselves and 28.6% answered as the caregiver on behalf of the patient. All patients had a caregiver. A definition of Heart Failure College was given to patients, and following this, they were asked if they had heard of it before then. Fifty-seven percent had heard of Heart Failure College before, and none of the patients had ever been participants in Heart Failure

College. Those who had previously heard of Heart Failure College recalled hearing that it is a once a week meeting on Fridays. After receiving the overview of Heart Failure College, 28.6% said they were extremely likely to attend, 28.6% were somewhat likely to attend, 14.2% were neither likely or unlikely, and 28.6% were extremely unlikely. Reasons keeping patients from attending Heart Failure College included the time commitment and being unwilling to do so. After given a list to choose as many methods that they would prefer to learn about the information taught in Heart Failure College, four answered that they would prefer paper reading material, four patients preferred discussions with Heart Failure College educators by phone or voicemail, and one patient preferred direction toward or access to online visual materials, as well as suggested having home visits by Heart Failure College educators. For patients who selected paper materials, they were asked if they preferred receiving paper materials in person or by post mail. Of the four patients that preferred paper materials, two preferred in person delivery, one preferred post mail delivery, and one patient did not have a preference between the two options. Patients were asked to rank four items in order of helpfulness, with one being most helpful and four being least helpful to determine when they would best like receiving disease management information. Some patients used numbers more than once if they were tied. The average score of receiving information on the day of the diagnosis was 2.1, and the average for receiving information sometime while they are in-patient status was 2.4. Receiving information once the patient transitions to out-patient status had a 2.7 average, and receiving information sometime after the first appointment had a 2.9 average. When asked what the Heart and Lung Center could provide for the patient, most did not answer or said they were unsure; however, one person stated they would like the Heart and Lung Center to be easily available for helpful instruction when they needed it. Only 28.5% of patients had heard of palliative care, and the definitions that came

to mind were comfort care, pain medication, and a step above hospice. None of the patients recalled being approached about receiving palliative care. When asked if they had enough resources to self-manage their health, 85.7% answered yes and 14.3% answered no. All patients were then asked the question “what do you need?”. Responses included home health, physical therapy, and financial assistance.

Table 2. Demographic information for patients who completed the out-patient survey.

Average Age	68.7 years old
Sex	
Male	85.7% (n=6)
Female	14.3% (n=1)
Marital Status	
Married	71.4%
Single/Widowed/Widower	28.6%
Separated or Divorced	0.0%
Family Doctor	
Yes	57.1%
No	42.9%
Employment Status	
Employed Full Time	14.3%
Employed Part Time	0.0%
Retired, disabled, or another unemployment	85.7%
Unemployed, but looking for a job	0.0%
Highest Education Level Completed	
Less than high school diploma	28.6%
High school diploma	42.9%
Some college	14.3%
Technical school	14.3%
Bachelor’s degree	0.0%
Master’s degree	0.0%
PhD or MD or JD	0.0%

Discussion

IN-PATIENT

The demographics of the cohort appeared to be in-tune with literature. Although there was a relatively even split of sexes who completed the survey, there was a higher population of

males compared to females, which correlates with the knowledge that males typically are more frequently affected by heart failure than females (Bui, Horwich, & Fonarow, 2011). The average age of the cohort, 65.2, also correlates with the knowledge that heart failure mostly affects individuals over the age of 65, and is in fact the leading cause of hospitalization for those over 65 years old ("Heart Failure Before Age 65: How Does It Happen?", 2017). As the majority of the population was of retirement age or disabled due to their heart condition, it was intuitive that most of them fit into the retired, disabled, or other unemployment category. Those who were employed, usually were the patients who were on the low age range and not yet at retirement age. Most patients had not completed any form of higher education, with only five of the 26 who went to either technical school or received their bachelor's degree or master's degree. It was interesting to find that only a limited amount of those with higher education were seen in the center for heart failure care because heart failure does not discriminate based on education level. The level of education could indicate how well the patient understood the information given to them about heart failure, and consequently, how they managed their heart health.

The average ranking of how active the patient was in general on a scale from one to ten was 4.6. This score was not surprising, as many of the patients who visit the Heart and Lung Center are post-discharge; therefore, they have recently had an exacerbation that decreases their ability to exercise due to shortness of breath or weakness. Many of the patients stated their current level of exercise was not where it used to be. For example, one patient ranked herself at three, but stated that prior to her hospitalization, she would have given herself a ten.

The diet plan for heart failure patients is rather bland, as they have to really limit their salt intake, eat plenty of fruits and vegetables, and choose lean meat. Salt has to be limited in the diet because it causes thirst, so the individual will drink more fluids, but it also causes the individual

to hold on to those fluids. This will cause swelling and make it harder to breathe and harder for the heart to do its job ("Your Diet if You Have Congestive Heart Failure", 2014). Due to these restraints, it was not predicted that patients would follow this well; however, the average score on a scale of one to ten of how nutritious the patients' diets were was 7.4. None of the patients ranked themselves below a five, which indicates the how the patients recognize the importance of their diet preventing heart failure hospitalizations. When they were educated about their diet, the medical professionals caring for the patients must have stressed this, and it appears to have resonated with the patients.

A list of topics was given to patients, asking if they could recall hearing or receiving information about each one. The list included aspects that are key to understanding one's heart failure diagnosis: nutrition, medication, daily weight, exercise, heart failure zones of care, and mood changes. If the patient is able to follow the guidelines that are linked to these topics, they will be more likely to manage their condition and also recognize when they need help. All patients should have been educated on all of the topics; therefore, asking them which they do and do not recall gives an idea of what information is sticking. In addition to the patient's score on their nutrition, another indication of the success of this topic arose when of the 26 patients, 25 recalled discussing and receiving information about nutrition with their provider. All patients remembered getting information about their medication, which makes sense because all providers take time to discuss what medication they are placing the patient on prior to prescribing it to them. Common medications prescribed to patients include those that help lower blood pressure and diuretics ("Medications Used to Treat Heart Failure", 2019). Lessening the blood pressure is important to prevent the heart from having to work as hard. Diuretics aid in removing excess fluid from the body, making it easier to breathe. It is vital for patients to

understand the importance of the medication they are taking because it greatly reduces their chance of readmitting, and it appears that these patients do know this.

Another high scoring topic was daily weight, with 25 remembering receiving information about it. Exercise was also highly recalled, with 24 patients remembering it. Logging daily weight is crucial to managing heart failure because it can be an early indicator of fluid retention. If a patient's weight increases more than three pounds in two days, it is likely that they are retaining fluid and need to contact the Heart and Lung Center ("Heart Failure Zones", 2018). Exercise has a variety of benefits for heart health. It strengthens the cardiovascular system and heart, gives individuals more energy, lowers blood pressure, and relieves anxiety and depression ("Heart Failure: Exercise Management and Treatment", 2019). Exercise can increase patients' strength, which may have been lost after a recent hospitalization due to heart failure.

Another topic, heart failure zones of care, did not score as high as the others. Only 19 recalled receiving or hearing information about it. The heart failure zones of care are a way for patients to recognize what warning symptoms should trigger them to call the Heart and Lung Center or go to the emergency room. There are three zones: green, yellow, and red. The green zone symptoms include the absence any of the following: shortness of breath, swelling, weight gain, chest pain, or decreased ability to maintain their activity level ("Heart Failure Zones", 2018). This zone symbolizes that the patient is doing well and has their symptoms under control. The yellow zone is the caution zone and includes weight gain of more than three pounds in two days, a cough, increased swelling, lethargy, dizziness, and increased shortness of breath with activity. These symptoms are signs that the patient needs to call the Heart and Lung Center and may indicate that they need to adjust their medications. The red zone is the alert zone, with symptoms of unrelieved shortness of breath even at rest, chest pain that cannot be relieved, and

confusion. If a patient was to experience any of these symptoms, they are to call 911 or go to the emergency room because they are experiencing life-threatening symptoms (“Heart Failure Zones”, 2018).

The mood change category did not resonate with the patients, as only 15 of the 26 recalled receiving information or hearing about it. Patients who experience heart failure are likely to develop depression due to not knowing what is coming, not feeling in control of their health, or not being able to do all of the activities they used to without being very fatigued. Having depression increases the chance of hospitalization because it can trigger events that threaten the heart. For example, depression can cause hypertension or elevate stress hormone levels that increase how much the heart has to work (“Depression and heart disease: a two-way street”, 2016). If a patient is experiencing symptoms of depression, it may make eating healthy, consistently taking their medication, and exercising harder than it already is. Anxiety is also common in patients with heart failure. It is important for heart failure patients to know that mood changes are linked to heart failure in order for them to be able to more easily recognize those feelings and consult with their care provider to prevent hospitalization.

Based on how the patients answered the previous questions, it was not surprising that many of them felt prepared to handle their heart health. The average score on a scale of one to ten was 7.8. The patients who were familiar with most or all of the topics previously discussed felt knowledgeable to handle themselves. Half of the patients had a caregiver, and many of the them indicated that they felt a high level of preparedness because they had the support and assistance from their family members. However, the average score of those with a caregiver was a 7.9 and the average of those without a caregiver was a 7.6, which are still relatively close.

The next portion of the survey focused on Heart Failure College. Patients were asked if they had previously heard of Heart Failure College. Only 53.9% of patients recalled hearing about it prior to that day. This response was not expected, as the nurse practitioner always explains Heart Failure College on the first visit. When asked what they thought of when they heard just the name of the program, the responses mostly reflected exactly what the program was about: patient education of heart failure at 65.4%. Other responses included heart attacks, unappealing because it was school, and fatal. Although it is good that the name Heart Failure College is intuitive to over half of the patients, it should also be noted that the name has negative connotation to other patients that may deter them from attending. As the majority of the target did not finish college, placing the word “college” in the name may lead patients to think that the program is tedious and boring.

The more shocking revelation of this section was the answers to whether or not patients planned on attending Heart Failure College after hearing a brief summary: only 23.1% said yes. Of the remaining 76.9%, 57.7% said no, and 19.2% were not sure. A large contributing factor to why patients did not want to attend was because they do not have time; however, this class meets only once a week for one hour over four weeks, totaling four hours over the course of one month. In addition, if the patient misses a class, they can always attend during the next cycle. Another response was that work conflicted with the time; therefore, some of those who said they do not have the time to attend and those who have work may benefit if there were different options on the time, rather than Friday at three o’clock. It is understandable that the class is only offered once a week because it runs cyclically and most of the patients are retired, but it limits the ability of those who work normal nine to five jobs from attending if they are interested. Other responses included that they were attending the cardiac rehabilitation program at the hospital or going

elsewhere to receive the same information. This was encouraging to see that although patients were not attending Heart Failure College, they were still obtaining helpful instruction in another form. It does not necessarily matter that the patients go to Heart Failure College, it matters that they are becoming knowledgeable in some way about how to manage their disease.

Palliative care was not a term that most patients were familiar with; therefore, when they were asked what it meant to them, most could not come up with a definition. Similar to Heart Failure College, all patients should have had a conversation with a health care provider about options to receive palliative care after being diagnosed with heart failure. It is unclear why patients did not recall the term. The word ‘palliative’ itself is not transparent or common, and this was apparent as most patients asked to have it repeated at least once when they were first asked if it was familiar. Another reason why patients may not remember palliative care could be on the provider end: it simply may not be stressed enough or communicated as a viable option for patients to proceed with.

Although 23.1% of patients recalled hearing the term palliative care, not all of them were able to come up with a definition for it. The few responses either defined palliative care as comfort care or linked it with hospice. This response supports the idea that there are misconceptions with palliative care. After receiving a definition of palliative care, patients were asked if they recalled being approached about receiving palliative care from a healthcare provider. Under eight percent answered yes. While some responded plainly that they had not, others had the same response but in a quicker and more confident manner, which hinted that they may not have fully understood what palliative care truly meant. For those patients, it may have still sounded similar enough to hospice that it seemed undesirable, or maybe it has to do with pride. As people age, they are not able to perform all of the tasks they used to, and heart failure

speeds along this process. Change in lifestyle and asking for help that stretches beyond visiting the doctor for physical ailments can be difficult after being mobile and independent for one's whole life. Consequently, palliative care to some may appear to be accepting that they will live their life with a disease they can only manage, not eliminate. Patients should know that palliative care is not care to be ashamed of receiving: it is a tool they can use to make the diagnosis of heart failure less of a burden. There are patients who would benefit from working with the palliative care team, but it seems as though most did not know palliative care even existed, let alone know what it could provide for them. This is problematic because patients whose quality of life have been severely affected could use the palliative care team to improve their life while coping with disease.

Possessing adequate resources is a large contributor to how well patients manage their heart health. Patients were asked if they felt like they had enough resources to self-manage, and most patients did at 88.5%. All patients were asked a follow-up question, regardless of how they answered: what do you need? Five of the 26 patients responded to this question, as most reiterated that they had felt like had sufficient means; however, the need for financial assistance was brought up multiple times. Many patients with heart failure have comorbidities, such as diabetes or kidney failure ("Comorbid Conditions Associated with Heart Failure", 2014). Due to possessing multiple diseases, patients are prescribed a handful of medications to take in order to manage all of their conditions. It is not uncommon for insurance companies to deny coverage for certain medications, leaving patients to go without the medication have to pay heavily out-of-pocket, as some medications have a hefty fee. In some cases, patients will also take lower than the prescribed dose to make the medication stretch farther. One patient stated that not only did they have diabetes in addition to heart failure, but their spouse was diagnosed with both as well.

They were both on disability and receiving money each month, but it was not enough to cover their bills, appointments, and medications all together. They both were taking the medications they could not do without, but had to sacrifice other medications because they were costing hundreds out of-pocket each month. In addition, having heart failure is like a double edged sword for some of the working patients who are not on disability because they need medication to improve their heart health in order to return to work, but their work insurance is not active and will not pay for their care because they are not working.

Although many patients stated they felt they had adequate resources and did not need anything, one patient elaborated. They explained that they only wanted to feel better and did not need anything else because they felt heavily supported by their family and loved ones. The help from their support system post-discharge has helped them feel like they can manage their health. The reason why many of the other patients did not feel like they needed any other resources or support could be because of loved ones helping them with their day-to-day needs and assisting in easing the transition into a new lifestyle; however, as there was only one patient that expressed this, it could be due to other reasons.

OUT-PATIENT

All seven patients were visited by the community paramedic and administered the out-patient survey. The demographics of this group were relatively similar to those who completed the in-patient survey. The average age of the cohort was 68.7. There were more males who completed the survey, but the ratio was higher: six of the seven participants were male, with only one female. Although more men are afflicted with heart failure, the imbalance is more likely due to the small sample size and the random seven who were able to be surveyed. Six of the seven

patients were retired or disabled, which also fits with the average age point. One patient went to technical school, but the rest of the group did not receive higher education. This could affect the patients' abilities to digest, comprehend, and act upon the information given to them about their diagnosis.

All but one patient felt like they had enough resources to self-manage, but needs were still listed when asked. One patient needed home health and physical therapy. Another needed financial assistance, which is not an unexpected response, due to the high cost of medications and the fact that most patients are living on a fixed income as a result of being disabled or retired. In combination with the results from the in-patient survey, patients with heart failure struggle with managing their health due to lack of financial stability. One issue that one patient expressed was not linked to any physical manifestation, but that they felt limited by their heart condition. Patients may have all of the help and contacts they can get, but that does not mean they feel fully in control of their diagnosis.

After being given a brief explanation of Heart Failure College, only four of the seven had heard of it prior to that visit, but none of the patients had participated. This was not necessarily surprising because some of the patients who were visited by the community paramedic were recently discharged from the hospital and had not yet been on-site to the Heart and Lung Center to receive their first post-discharge consultation with all of the information; however, during the visit the community paramedic usually introduces Heart Failure College as an option to help patients gain a better understanding of heart failure. As many of the patients the community paramedic visits are being seen for the first time by a medical professional since their hospitalization, it also is comprehensible that they would not yet have attended the program.

Those who had heard of Heart Failure College before were asked what they remembered hearing about it, and all remembered that it was weekly and on Fridays, but none mentioned the purpose or activities involved in the program. This was interesting because the name “Heart Failure College” seems self-explanatory, but that was not the information that remained with the patients. The likeliness of the patients attending in the future did not display a unanimous response, but rather a relatively equal distribution across all responses. The responses do not indicate a strong desire of the population to attend or not to attend. Patients’ reasons for not attending Heart Failure College only included time commitment and unwillingness. The time commitment response, similar to the in the in-patient survey, was not a highly anticipated response due to the small amount of time the program takes: four hours over a course of four weeks. In addition, it was a shocking revelation that patients freely admitted that they would not attend simply because they did not want to go and nothing more. In fact, one patient stated they were unwilling, and when asked why, they replied that they were too stubborn. The attitude of not wanting to make improvements and changes to one’s life because they are reluctant to do so is not likely one that providers alone are able to sway. Unwillingness is not an indicator of how well the provider has prepared them to manage because they may fully grasp all of the information but will not act upon it. This stubborn mindset more than likely contributes to the number of re-admittances, but this cannot be blamed on the medical professionals.

The most popular options for learning preference of Heart Failure College material were paper reading or visual materials and discussions with Heart Failure College educators by phone or voicemail. It is logical for these patients to prefer paper materials as opposed to online reading materials, which was another option, because of the accessibility aspect. Although there are always exceptions, generally younger people prefer online resources more than those who are

older due to the internet being difficult to grasp if one did not learn how to use it at a younger age. Paper materials allow the patient to have immediate access to all of the information in their hands without having to use a smartphone or computer. A preference between receiving paper materials in person or by post mail was not clearly indicated.

Discussing information via phone call or voicemail is also logical because it allows patients to hear the information explained in a possibly more succinct and comprehensible manner as opposed to reading materials or communicating via text messaging. Phone calls also provide a way for patients to ask questions and receive immediate feedback. One patient preferred direction toward or access to visual materials such as videos, graphs, charts, and pictures due to not being able to comprehend reading material well. Videos may be wise to implement as an off-site way of giving information due to it sometimes being able to tie together difficult topics in a complete and easy to understand manner with visual contexts. There is no right or wrong preference: the preference of the patients can vary based what type of learner they are. Those who are visual learners may prefer pictures and charts, where an auditory learner may prefer phone calls.

One patient also recommended providing patients with the option of having home visits by Heart Failure College educators. This is an idea that may cause others to have a greater interest in Heart Failure College; however, it may not be feasible, especially if patients live far away, because the educators have other jobs than Heart Failure College, and individual home visits would require a great deal of time and money. As it is right now, Heart Failure College has the capability educate a group of people at once, but implementing home visits would make that process go much slower.

Patients were given options to rank when receiving information about their diagnosis would be helpful, with one being most helpful and four being least helpful. The averages of all of the scored options were not truly indicative of when patients preferred receiving information because the averages were all relatively close. The lowest, and thus most helpful, to this group was receiving disease management information on the day of the diagnosis at 2.1. The second lowest at 2.4, was receiving disease management information sometime while the patient is in in-patient status. Obtaining information once the patient transitions into out-patient status and sometime after the first out-patient appointment were the highest at 2.7 and 2.9 respectively. Some patients did not rank one through four, but instead tied some of the options, which contributed to the closeness of all of the scores. From this information, it appears that patients preferred hearing disease management the day of their diagnosis and did not want to hear the information after their first out-patient appointment. It comes as a surprise that patients would want to begin learning how to manage their heart failure the day they are diagnosed because that is likely when they have had a full exacerbation leading them to go to the hospital or emergency room, making for a chaotic and overwhelming day. As all of the patients surveyed had a caregiver, one explanation for this choice could be that they may be able to rely on that person to also listen to the information being explained and aid in reminding the patient of changes that need to be made, which could ease the post-discharge transition. Patients could have scored receiving information sometime after their first out-patient appointment as least helpful because they may feel like they are clueless on how to better their lifestyle and prevent another hospital visit in the time between their discharge and after their first out-patient visit.

The majority of the patients did not have an answer for what the community paramedic and the Heart and Lung Center could provide them. In fact, only one patient answered, stating

that having the center easily available for helpful instruction or if they have a question. Ease of contact is one value the Heart and Lung Center prides themselves in, and patients are almost always able to talk directly to the nurse practitioner or community paramedic when they call the center; therefore, it is good to see that one of the patient requests is already a priority of the center.

Similar to the in-patient survey, most patients were unfamiliar with the concept of palliative care. The two patients familiar with palliative care produced definitions of a step above hospice, comfort care, and pain medication, displaying the lack of knowledge of palliative care's depth. None of the patients recalled being approached about palliative care, but again, this option of care should have been discussed with them at some prior point.

Overall, the results from the out-patient survey provided some information about patient knowledge and preference; however, the sample size was too small to be representative of the whole population of patients visited by the community paramedic. Additionally, for a number of the questions, the small sample size provided some instances where patients were evenly split between options, with no real "best answer". This could hold true even if more patients were surveyed, but real conclusions cannot be drawn because only seven patients were surveyed.

One interesting aspect of the Heart and Lung Center was the space of the center itself. It is located within the cardiology and pulmonology center. After entering a small corridor, the Heart and Lung Center is only comprised of one rather small office where the nurse practitioner and community paramedic work and two patient rooms down the hallway. From an outside perspective, the space appears relatively mobile, as if the idea of the center was created and this small empty space was available to fill. This observation may or may not affect patient perception of the type of care they may receive or the resources they have available to them.

Takeaways for the Community Partner

Patients' responses from in-patient survey appeared to give similar trends. Most remembered the key terms related to heart failure management: nutrition, medication, daily weight, and exercise. There seemed to be a disconnect with heart failure zones of care and mood changes, as a lower percentage of patients recalled these terms. These two ideas should be stressed more when patients are visiting the center in order to gain a better understanding and have the information stick. It is imperative for patients to have a grasp of heart failure zones of care because it tells them when they should contact their provider or go to the emergency room based on the symptoms they are having. If patients are not confident recognizing the zones, they may not get help when they truly need it.

The only ranking from one to ten section in the in-patient that did not have a relatively high average was the one involving activity. The importance of activity is stressed heavily by health care providers, but the average remains low. It is difficult to say what will motivate patients to be more active given how hard much effort the team invests in this area, but perhaps it could be helpful to continue to work with the patient to present them with an exercise plan that meets them where they are at, and helps gradually increase the amount of activity they are able to perform throughout the day. Again, I know the team is making every effort to do just this so persistence may be the only option. If patients have a plan that seems achievable daily, they may be more likely to follow through with it. The other scoring sections, nutritious diet and how prepared the patient felt to manage their heart health, had higher scores. This indicates that patients have made a connection with the instruction that they have been given by their providers about the importance of their diet because most have implemented it into their daily lifestyle to a

fairly high degree. The confidence of the patient exhibited by their preparedness also reflects the effectiveness of Heart and Lung Center's teaching in most regards.

In regards to attendance of Heart Failure College, the overall response was not leaning in a positive direction. The responses brought up the most that did not involve hearing the same information elsewhere were not being able to attend due to work conflicts, living too far away, or the time commitment. Due the large amount of people who cannot physically come to the hospital, it could be beneficial to create diverse methods to learn the same information. It would be most helpful to create diverse methods as opposed to one, such as just paper materials, because patients learn in different ways. If there are multiple ways to learn the same information, more patients may be willing to use the services in a way that best fits their needs and learning style.

Palliative care across the board was a concept patients were not familiar with hearing. Since it is not a word used much in everyday language it was not familiar to patients even through causal contact. If this concept is consistently being discussed with patients, it would be recommended that another approach be attempted. For some reason, this term does not stick with patients; therefore, a lengthier conversation may be necessary to fully communicate what it can provide for patients if the provider wants patients to have the option to receive it. Patients cannot request care they do not know about, so it is advantageous to introduce them to palliative care. It can be done at any point of their diagnosis because even though if they may not feel like they need it that moment, it can be an option for the future if they so choose.

Study Limitations and Recommendations for Future Research

As the study only ran for a limited amount of time, only a limited amount of patients who visited the Heart and Lung Center or who were visited by the community paramedic were able to

be surveyed. In addition, many of the out-patient surveys collected were given to the patients by the community paramedic himself. This could potentially change the responses of the patients because they may feel pressured to answer in a way that favors the community paramedic for fear that his perception or treatment towards them may change. It is recommended that in the future when performing a program evaluation, those administering the survey should not be affiliated with the Heart and Lung Center in order to limit the deviation of patient responses.

Originally the team of interns were supposed to give the surveys to the patients when the principal investigator was not at the Heart and Lung Center; however, this did not work as well as expected. The staff and the interns at the Heart and Lung Center take patients' vitals, listen to their concerns, educate patients on their diagnoses, and provide courses of treatment; therefore, they are relatively busy throughout the course of the day. Although the surveys were to evaluate the effectiveness of patient education and improve it in the future, the surveys could not take first priority when the principal investigator was not there to administer the surveys due to the staff needing to focus on current patients' needs.

In an ideal world and for this evaluation in the future, it would be suggested to have one person or multiple people whose sole focus is on administering the survey 40 hours each week until the goal is met. This would allow for the maximum amount of patients to be reached within a shorter timeline without having other responsibilities that sidetrack the research. Consequently, this method would provide more data to display to the Heart and Lung Center to improve their patient care.

Another recommendation for improving the smoothness of the study involves the group administering the survey. From this experience, the engagement of the group is imperative for the study to progress in a functional manner. Each person involved on the research side needs to

feel connected to the study or else the purpose and motivation to complete the study is lost. If each individual feels personal responsibility for some part of the research, they will feel more connected to the study instead of a bystander who has no stake in the research.

Administering the survey on the day of the appointment in the same room the patients were just seen in may have unintentionally altered some responses. Although I identified myself as separate from the Heart and Lung Center and only as a researcher completing a program evaluation, I am unsure if patients still considered me as that because we were still in the Heart and Lung Center. For example, when one patient was asked how prepared they felt to manage their heart health from that point forward on a scale of one to ten, they initially said ten after some hesitation. They then expressed that they did not actually think they were that prepared, but felt as though the question was a "catch 22" because the Heart and Lung Center had practically saved their life and they did not want to say anything that would indicate that the center had not properly prepared him to manage. This was even after I explained that the question stressed how prepared they personally felt as opposed to directly how well they felt the center had prepared them. Thus, in the future, it may be important to relocate patients to another part of the hospital to administer the survey in order to allow them to see a more physical separation between the survey and the health professionals providing care in the center.

Thoughts as a Future Health Care Provider

Overall, the research performed was eye-opening for me, as a future physician. I was shocked to see that although heart failure patients do have a large amount of autonomy over how their disease progresses, there are those who are unwilling to take control of their actions. A health care provider can only provide a certain amount of care to the patient, until it is in the

patient's hands. Ultimately, the provider cannot keep the patient out of the hospital if they are non-participatory in doing what they need to do to keep their heart functioning properly. A great example of this is when a patient was asked why they chose not to attend Heart Failure College, they replied, "I am educated far beyond my level of obedience." I was floored by this. The patient knew how important it was to eat healthy, exercise, take their medication, along with many others; however, this did not change their outlook on how they chose to behave. The mindset here is one of "doing whatever I am doing has kept me alive so far, so why would I change?" Another patient said if they would have listened the first time they attended Heart Failure College, they probably would not have been hospitalized the last time. Conversely, when the same patient was asked if they would attend Heart Failure College again, they replied, "I already went once, why would I go again?" They had already answered that question when they previously stated that paying attention could have prevented another hospital visit.

Although there were patients who were set on not changing their ways, they did not make up the entirety of the cohort. When I discussed Heart Failure College with some of the patients, they were very interested in what it had to offer them and what they could learn. It was uplifting to see that even people who made up the top of the age range were engaged and committed to changing their lifestyle to not only prolong their physical life, but also their quality of life.

In addition to learning about the patients, I also learned a great deal about research in the field. Prior to this, I had some notion that it would not be extremely difficult to gather 30 surveys of both the in-patient and out-patient survey in one month. This was far from the case. Although the nurse practitioner and community paramedic were not opposed to the research and supported it, it was clear that it was not a priority. It was not due to any ill reason, it was simply because they had many other focuses during the work day, specifically providing quality care to the

patients. The surveys were not even relatively near that level of importance. This learning experience, I believe, has prepared me for being a future provider in a hospital setting. A thought to consider is how I will react as a provider if a student wants to perform a program evaluation for the patients I care for. From being the student performing the research, I see the importance of giving providers feedback on what information patients are and are not remembering, their self-care confidence levels, as well as reasons why they choose not to attend a free beneficial program. As a provider, however, it is more than likely difficult to focus on many extra activities besides caring for patients and charting; therefore, surveys are not on the top of the priority list or even close. It will be important to remember that I can only gain a better understanding of how well I am caring for my patients, and that the study directly affects me and my patients. The survey assists in gauging the level of receptiveness of the patient, as well as the effectiveness of the communication between the provider and the patient; consequently, this can lead providers alter their teaching style to improve their care.

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Appendix A: IRB Decision

Office of Research Integrity
Institutional Review Board (IRB)
2000 University Avenue
Muncie, IN 47306-0155
Phone: 765-285-5052
E-mail: orihelp@bsu.edu

DATE:	February 20, 2019
TO:	Marisa Hochstetler
FROM:	Ball State University IRB
RE:	IRB protocol # 1376000-2
TITLE:	Hope after Failure: Heart Failure Patient Education
SUBMISSION TYPE:	Revision
ACTION:	**DETERMINATION OF NOT HUMAN SUBJECTS RESEARCH**
DECISION DATE:	February 20, 2019
REVIEW TYPE:	Expedited Review

The Institutional Review Board (IRB) received the above protocol. After review and consideration, the IRB concluded that this project does not meet the federal definition of 'research with human subjects' at this time, as specified by federal regulations at 45 CFR 46.

Research: A systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge.
(Activities which meet this definition constitute research for purposes of this policy, whether or not they are conducted or supported under a program which is considered research for other purposes.)
For the purposes of this part, the following activities are deemed not to be research:

1. Scholarly and journalistic activities (e.g., oral history, journalism, biography, literary criticism, legal research, and historical scholarship), including the collection and use of information that focus directly on the specific individuals about whom the information is collected.
2. Public health surveillance activities, including the collection and testing of information or biospecimens, conducted, supported, requested, ordered, required, or authorized by a public health authority. Such activities are limited to tallow a public health authority to identify, monitor, assess, or investigate potential public health signals, onsets of disease outbreaks, or conditions of public health importance (including trends, signals, risk factors, patterns in diseases, or increases in injuries from using consumer products). Such activities include those associated with providing timely situational awareness and priority setting during the course of an event or crisis that threatens public health (including natural or man-made disasters).

3. Collection and analysis of information, biospecimens, or records by or for a criminal justice agency for activities authorized by law or court order solely for criminal justice or criminal investigative purposes.
4. Authorized operational activities (as deemed by each agency) in support of intelligence, homeland security, defense, or other national security missions.

Human Subject: A living individual about whom an investigator (whether professional or student) conducting research (1) obtains information or biospecimens through intervention or interaction with the individual, and, uses, studies, or analyzes the information or biospecimens; or (2) obtains, uses, studies, analyzes, or generates identifiable private information or identifiable biospecimens.

This does not necessarily mean your project is not research, and decidedly does not mean your project is not important. It simply means your project does not fall under the purview of the IRB. Consequently, this project does not require IRB approval as submitted. The IRB accepts this information for our records and will retain it in our files. Thank you for providing the IRB with these materials for review. Please contact the Office of Research Integrity if any details of the study are to change so that the IRB may reconsider the protocol, if necessary. You are welcome to proceed with your project as it was presented to the ORI, though we do not take any responsibility for the protection of your participants.

If you have any questions regarding this decision or would like to respond in person, please contact Sandra Currie at (765) 285-5052 or slcurrie@bsu.edu.

Appendix B
Partners in Education
In-Patient Survey

Please take a few minutes to answer these questions so that we can better serve you.

1. Do you know what medical issue brought you to the hospital today?

2. How many times have you been treated in a hospital or emergency room for this condition?

3. On a scale of 1 to 10, how active would you say you are in general? (1 being not active at all and 10 being the most active one can be)

1 2 3 4 5 6 7 8 9 10

Not active at all Neutral Very active

4. On a scale from one to ten, how nutritious is your diet? (1 being not nutritious and 10 having a very nutritious diet?

1 2 3 4 5 6 7 8 9 10

Not nutritious at all Neutral Very nutritious

5. What information can you recall receiving from the medical professionals about your heart condition? Information about: (Circle all that apply)

a. Nutrition
b. Medication
c. Daily weight
d. Exercise
e. Heart failure zones of care
f. Mood changes

6. On a scale of one to ten, how prepared do you feel to manage your heart health from this point forward? (1 not prepared and 10 very prepared)

1 2 3 4 5 6 7 8 9 10

Not prepared at all Very prepared

7. Do you have a caregiver? Yes / No. If yes, what is their relationship to you?

_____

8. Have you heard of the Heart Failure College? Yes No Not sure

9. When you hear the name of this program, what does it make you think of?

10. Do you plan to attend the Heart Failure College?

    Yes No Not sure

    If no or not sure, why not?

    If yes, will a caregiver or loved one be attending the program with you?

    Yes No Not sure

11. Have you heard of palliative care?

    Yes No Not sure

12. What does palliative care mean to you?

    _____
    _____
    _____

13. Have you been approached about receiving palliative care?

    Yes No Not sure

Palliative care is specialized medical care for people with serious illness and focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

The following questions will be used only for the purpose of classification. Your responses will not be tied to your identity in any way. You do not have to answer these questions if you are not comfortable doing so. Thank you for your time.

1. What is your sex? (Please circle one) Male Female Other Prefer to not say

2. What is your age? _____

3. What is your current marital status? (Please circle one)

    o Married o Single/Widowed/Widower

- o Separated or divorced
- o Prefer to not say

4. Do you have a family doctor? _____

5. Do you feel like you have enough resources to self-manage?
   - o Yes
   - o No

6. What do you need?
   _____
   _____
   _____

7. What is your current employment status? (Please circle one)
   - o Employed full time
   - o Employed part time
   - o Unemployed, but looking for a job
   - o Retired, disabled or another unemployment/not looking for job

8. Highest Education Level Completed? (Please circle one)
   - o Less than high school diploma
   - o High school diploma
   - o Some college
   - o Technical school
   - o Bachelor's degree
   - o Master's degree
   - o PhD or MD or JD
   - o Prefer to not say

Appendix C
Partners in Education
Out-Patient Survey

Please take a few minutes to answer these questions so that we can better serve you.

14. Where are you currently receiving out-patient treatment for heart failure?

    - o Community Paramedic
    - o Outpatient Center
    - o Home Care

15. Please select the status that best applies to you.

    - o Patient
    - o Caregiver on behalf of the patient
    - o Caregiver on behalf of themselves

16. *A caregiver is a family member, friend of paid helper who assists you in your daily activities.*

    Do you have a caregiver?

    Yes No

17. *Heart Failure College is a free and voluntary educational program that aims to improve the quality of care our hospital provides, the quality of life and life expectancy of our patients, and reduce hospital admissions in heart failure. The program contains multiple educational sessions led by nurses, nutritionists, and pharmacists with the goal of providing disease management skills.*

    Had you heard of Heart Failure College before now?

    Yes No

18. Have you ever been a participant in Heart Failure College?

    Yes No

If patient has heard of BUT not been a participant in Heart Failure College ask Question 6

19. What keeps you from participating in Heart Failure College? Please select all that apply.

    a. Not enough information
    b. Lack of reliable transportation
    c. Time commitment
    d. Unwilling to attend (If so, why?)
    e. Other

    _____
    _____
    _____

If patient has been a participant of Heart Failure College, ask Question 7

20. Describe your experience with Heart Failure College.

    _____
    _____
    _____
    _____

If patient has neither heard of Heart Failure College nor attended, ask Questions 8-10

21. What information do you recall hearing?

    _____
    _____
    _____
    _____

22. After receiving a brief overview of Heart Failure College, how likely are you to attend?
    - o Extremely likely
    - o Somewhat likely
    - o Neither likely nor unlikely
    - o Somewhat unlikely
    - o Extremely unlikely

If answered somewhat unlikely or extremely unlikely, ask Question 10

23. What keeps you from participating in Heart Failure College? Please select all that apply.

    a. Not enough information
    b. Lack of reliable transportation
    c. Time commitment
    d. Unwilling to attend (If so, why?)
    e. Other

    _____
    _____

---

24. What are ways you would prefer learning the information taught in Heart Failure College without having to come on-site? (Please select all that apply)

    - o Paper reading materials (reading, visuals)
    - o Direction toward or access to online reading materials (e.g. news articles, journal articles, validated guides)
    - o Direction toward or access to online visual materials (e.g. videos, graphs, charts, pictures)
    - o Heart Failure College course offered online
    - o Discussions with Heart Failure College educators by phone/voicemail
    - o Discussions with Heart Failure College educators by text messaging
    - o Other _____

If patient selected Paper reading materials, ask Question 12

25. How would you like to receive your paper materials?

    o In Person o Post Mail

26. Please rank each of the following items in order of "helpfulness", where 1 signifies "most helpful" and 4 signifies "least helpful".

    _____ It would be helpful to receive disease management information **the day of my diagnosis**.

    _____ It would be helpful to receive disease management information **sometime while I am of in-patient status**.

    _____ It would be helpful to receive disease management information **once I transition to out-patient status**.

    _____ It would be helpful to receive disease management information **sometime after my first out-patient appointment**.

    _____ I do not want to receive information about disease management

27. What can we provide for you?

    _____
    _____
    _____

28. Have you heard of palliative care?

    Yes No Not sure

29. What does palliative care mean to you?

    _____
    _____
    _____

30. Have you been approached about receiving palliative care?

    Yes No Not sure

Palliative care is specialized medical care for people with serious illness and focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

The following questions will be used only for the purpose of classification. Your responses will not be tied to your identity in any way. You do not have to answer these questions if you are not comfortable doing so. Thank you for your time.

9. What is your sex? (Please circle one) Male Female Other Prefer to not say

10. What is your age? _____

11. What is your current marital status? (Please circle one)

    - o Married
    - o Single/Widowed/Widower
    - o Separated or divorced
    - o Prefer to not say

12. Do you have a family doctor? _____

13. Do you feel like you have enough resources to self-manage?
    - o Yes
    - o No

14. What do you need?

    _____
    _____
    _____

15. What is your current employment status? (Please circle one)
    - o Employed full time
    - o Employed part time
    - o Unemployed, but looking for a job
    - o Retired, disabled or another unemployment/not looking for job

16. Highest Education Level Completed? (Please circle one)
    - o Less than high school diploma
    - o High school diploma
    - o Some college
    - o Technical school
    - o Bachelor's degree
    - o Master's degree
    - o PhD or MD or JD
    - o Prefer to not say